

**REPORT TO THE TWENTY-THIRD LEGISLATURE
STATE OF HAWAII
2005**

**PURSUANT TO SECTION 321-291, HAWAII REVISED STATUTES
REQUIRING THE DEPARTMENT OF HEALTH TO GIVE AN
ANNUAL FINANCIAL REPORT FOR THE
NEWBORN METABOLIC SCREENING SPECIAL FUND**

**PREPARED BY:
STATE OF HAWAII
DEPARTMENT OF HEALTH
DECEMBER 2004**

EXECUTIVE SUMMARY

The Hawaii Newborn Metabolic Screening Program (NBMSPP) is administered by Children with Special Health Needs Branch, Hawaii State Department of Health. NBMSPP has statewide responsibilities for assuring that all infants born in the State of Hawaii are tested for phenylketonuria (PKU), congenital hypothyroidism, and other diseases that are added to the screening panel. This program tracks and follows up on infants to assure satisfactory testing and to assure that infants with the specified diseases are detected and provided with appropriate and timely treatment. The objectives are to prevent mental and growth retardation, severe health problems, and even death, resulting from disorders detectable through newborn metabolic screening.

In 1996, legislation was passed, H.R.S. §321-291, which established a newborn metabolic screening special fund which is used for operating expenditures, including, but not limited to, laboratory testing, follow-up testing, educational materials, continuing education, quality assurance, equipment, and indirect costs.

The Hawaii Administrative Rules, Chapter 11-143, revised and adopted on November 20, 2003, reflect the following changes:

- Expansion of the newborn metabolic screening testing battery to include tests for:
 - Phenylketonuria (PKU)
 - Congenital Hypothyroidism
 - Galactosemia
 - Hemoglobinopathies
 - Congenital Adrenal Hyperplasia (CAH)
 - Maple Syrup Urine Disease (MSUD)
 - Biotinidase Deficiency
 - Amino Acid Disorders
 - Fatty Acid Oxidation Disorders
 - Organic Acid Disorders
 - Urea Cycle Disorders

- Newborn screening fee increased from \$27.00 to \$47.00 per specimen collection kit beginning September 1, 2003. The fees are deposited in the newborn metabolic screening special fund, which pays for the following expenses:
 - Centralized laboratory testing for the thirty-one disorders
 - Repeat testing for initial specimens collected at less than 24 hours of age
 - Confirmatory testing up to the point of diagnosis if specimens are sent to the designated testing laboratory
 - Specimen collection and handling
 - Overnight mailing costs of the initial specimens to the testing laboratory
 - Newborn Metabolic Screening Program staff salaries and fringe benefits
 - Contracted nutritionist, pediatric metabolic specialist; pediatric endocrinologist; and pediatric hematologist services
 - Screening and diagnostic costs for the uninsured indigent
 - Tracking and follow-up, and the administration of the statewide newborn screening system
 - Continuing education
 - Educational materials
 - Quality assurance
 - Equipment
 - Indirect costs
 - Administrative overhead

The attached financial report for FY 2004 (July 1, 2003 to June 30, 2004), required by § 321-291, HRS, identifies all fund balances, transfers, and expenditures made from the newborn metabolic screening special fund and the purposes for each expenditure.

Report on Non-General Fund Information

Department: HEALTH

Date:

September 13, 2004

Prepared by:

Calvin Kunihisa

Phone:

586-4559

Name of Fund: Newborn Metabolic Screening Special Fund

Legal Authority: Section 321-291, HRS

Fund Type (MOF): B

Approp. Acct. No. S 302 H

Intended Purpose:

This fund is to be used for payment of its lawful operating expenditures, including, but not limited to laboratory testing, follow-up testing, educational materials, continuing education, quality assurance, equipment, and indirect costs.

Current Program Activities:

The Newborn Metabolic Screening Program (NBMSPP) has statewide responsibilities for assuring that infants born in the State of Hawaii are satisfactorily tested for 31 disorders which can cause mental and growth retardation and even death, if not detected and treated early in the newborn period. NBMSPP tracks and follows-up on infants to assure that the infants with the specified diseases are detected and provided with appropriate and timely treatment. Other activities are assessment, quality assurance, continuing education, and standard setting.

Financial Data		
	FY 2004	FY 2005
Beginning Cash Balance	325,345.53	554,078.45
Beginning Encumbrances	113,875.39	138,112.79
Revenues	908,062.28	
Expenditures	646,179.38	
Transfers (List Each Transfer by JV# and Date)		
JV #JM2549 dtd 12/8/03	33,149.98	
Net Total Transfers	33,149.98	
Amount Derived from Bond Proceeds		
Ending Cash Balance	554,078.45	
Amount Required for Bond Covenants as of 7/1/01		
Amount held in Certificates of Deposit, Escrow Accounts, or Other Investments as of 7/1/01.		

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PURPOSES FOR EXPENDITURES FOR FY 2004

I.	Newborn Metabolic Screening Program Personnel Costs	
A.	Payroll (3 FTE)	\$197,869.28
B.	Car Mileage	598.94
II.	Implementation of newborn screening system utilizing a centralized laboratory	
A.	Oregon State Public Health Laboratory	400,325.07
B.	FedEx services to deliver specimens to the testing laboratory	30,468.37
C.	Shelving for network server and workstation	392.08
D.	Back-up tapes	485.66
E.	Tyvek envelopes for the mailing of specimens to laboratory	1,493.70
F.	Fax machine maintenance	308.88
G.	Notice of public hearing in four major newspapers	1,108.46
H.	Stationary and office supplies	1,728.82
I.	Postage	5,000.00
J.	Disposal of forms	160.00
III.	Continuing education	
A.	2004 Newborn Screening and Genetic Testing Symposium, Atlanta, Georgia, 5/3/04–5/6/04	1,597.32
B.	In-service to nurses, physicians, and laboratory staff on Maui	30.00
C.	Subscription to <u>National PKU News</u>	18.00
D.	Bilingual Access Line translation services	82.00
IV.	Air and ground transportation for endocrinologist services on the Neighbor Islands	1,096.00

V.	Nutrition services for clients with metabolic disorders	3,416.80
	TOTAL	<u>\$646,179.38</u>

JV #JM2549 Assessments for central services and administrative expenses for FY 03	\$33,149.98
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BEGINNING ENCUMBRANCES FY 2005

Personnel	\$13,528.00
Mileage	11.09
Oregon State Public Health Laboratory	37,550.76
Hawaii Community Genetics	50,000.00
FedEx courier services	616.04
Fax machine maintenance	65.92
Other supplies	291.17
Public hearing legal ad	5.81
Neighbor island travel	404.00
Shuttle to and from the airport for the Newborn Screening Symposium	40.00
Registration fee for the Newborn Screening Symposium	250.00
Newborn screening laboratory services for the indigent/uninsured	350.00
Assessments for central services and administrative expenses for FY 04	<u>35,000.00</u>
TOTAL	\$138,112.79